Recommendations

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1 Choice of medicine should be negotiated between the individual and the doctor. It should be based on the assessment of need, the benefit and side effect profile of each medicine and the relative importance of these to the person's quality of life.

2 The medicine should be reviewed regularly (at least twice a year) and alternatives made available if the first choice is proving ineffective or producing unwanted side effects.

3 Where discussion between the individual and the doctor is not possible or in cases of doubt, atypical antipsychotics should be preferred because of their lower risk of Extra Pyramidal Side Effects and Tardive Dyskinesia.

4 Where typical antipsychotics are used, doses should be kept at the lowest therapeutic dose and frequent monitoring for all side-effects should be conducted.

5 Where an individual has not responded to typical or atypical medicine clozapine should be prescribed.

6 When a change in medicine takes place doctors should ensure that appropriate support is available to assist people with the change.

7 Atypical antipsychotics should be the first-line default medicine prescribed for people with symptoms of psychosis.

"Each patient should ideally be prescribed only one antipsychotic, preferably in a single dosage form"

The Maudsley Prescribing Guidelines 2001

At present people with schizophrenia are generally getting cheaper medicines with poorly tolerated side-effects when better medicine is available, and in mental healthcare .... that's just typical.

For further findings from the research, including method and limitations please access the nsf website at www.nsf.org.uk/information/research/

This report was written by: Paul Corry, Gary Hogman and George Sandamas.

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positive response to mental illness nsf

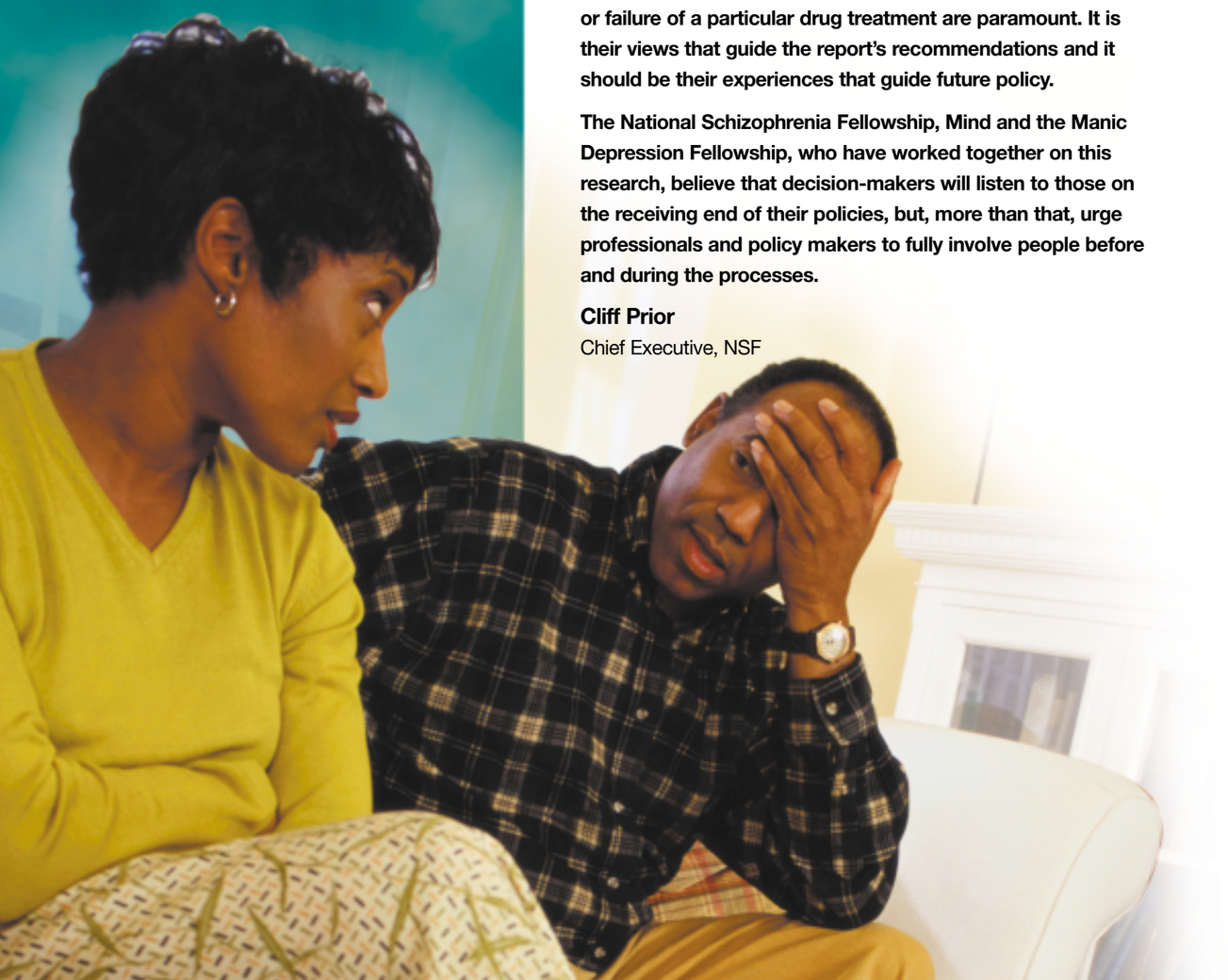
That's Just Typical

"I was no longer a being with feelings, ideas, beliefs, points of view or a future. All I was, was the recipient of a specific drug and that was it."

Preface

Anne from London says

"Too often professionals pigeon-hole people with mental illness and treat them as hopeless cases"



This report follows *A Question of Choice*, published in 2000. Like the first report, which highlighted the lack of choice offered to people, *That's Just Typical* draws on findings from the largest ever survey of people using medicines for the treatment of severe mental illnesses. This new report narrows the focus to people taking antipsychotics for a diagnosis of schizophrenia. It looks at people's experiences of using a range of drug treatments, how well-suited they found them and which drugs they found tolerable and intolerable.

The results are in some places shocking, in others astounding. They clearly indicate people's preferences for atypicals.

These two reports, and further ones to follow, offer a fresh perspective to the reams of research that has, over many years, undervalued the voice of the person with severe mental illness in favour of randomised control trials. Here, the views of people whose lives are dramatically affected by the success or failure of a particular drug treatment are paramount. It is their views that guide the report's recommendations and it should be their experiences that guide future policy.

The National Schizophrenia Fellowship, Mind and the Manic Depression Fellowship, who have worked together on this research, believe that decision-makers will listen to those on the receiving end of their policies, but, more than that, urge professionals and policy makers to fully involve people before and during the processes.

Cliff Prior
Chief Executive, NSF

Introduction & Method

The National Institute for Clinical Excellence has been asked by government to compare so-called "atypical" medicines for schizophrenia with older and cheaper medicines, the so-called "typicals." Existing research has not asked the people who take these two types of medicine how they compare with each other, or which of the two types of medicine is their preferred choice. The National Schizophrenia Fellowship, the Manic Depression Fellowship and MIND, the three largest mental health membership charities in the UK, conducted this survey to discover the missing evidence. Around 15,000 questionnaires were distributed through NSF, MIND and MDF mailing lists. 2,663 people replied. 2,222 (85%) had direct experience of a mental illness, while 387 (15%) were informal carers.

In addition, 10 focus groups - five with service users and five with carers - were organised. Quotes throughout this report are drawn from these focus groups.

Over 400 different medicines were recorded by survey respondents. The older "typical" antipsychotics were the most prescribed drugs in our survey. They are used in the treatment of schizophrenia, severe anxiety and the manic phase of manic-depression.[1]

The findings reported below are from a sub-group of the respondents. In order to reduce the number of possibly confounding variables, only the responses from people with a diagnosis of schizophrenia who were in receipt of an antipsychotic as their first medicine (525 people) were included. Of these, 34% were women, 64% men with 2% not submitting their gender. The average age of these respondents was 41; age range 19 to 78. Almost all respondents classified themselves as white.

Polypharmacy, the use of a "cocktail" of medicines, may be used with people who have more than one diagnosis, to counteract the unwanted side effects of another medicine or enhance a specific therapeutic action. Our study has found that over 16% of respondents with schizophrenia were on two or more antipsychotics. People with schizophrenia who experience side-effects from their antipsychotic medicines may be given anti-cholinergics to counteract them. There are several problems with polypharmacy, not least the confusion it can cause in trials designed to identify the therapeutic benefits or side effects of a particular medicine, and the risks of a drug interaction developing. Good practice dictates that people should receive only one antipsychotic and, preferably, in a single dosage form.[4,5]

Table One: Demographic information

Gender	
Women 1,398 (53%)	Men 1,265 (47%)
Ethnic origin	
White 2,408 (91%)	Other 255 (9%)
Average age	
People with a mental illness 45	Carers 51
Age range	
People with a mental illness 16 to 98	Carers 19 to 95
Main diagnosis	
Schizophrenia 969 (37%)	Manic Depression 890 (34%)
Depression 547 (21%)	Personality Disorder 49 (2%)
Other 189 (7%)	

Table Two: What medicines?

Types of medicines	First medicine recorded	All medicines recorded
Antipsychotic: Typical	614 (23%)	1266 (26%)
Antipsychotic: Atypical	470 (18%)	646 (13%)
Anti-Depressants	491 (18%)	1063 (22%)
Mood Stabilisers	539 (20%)	1002 (20%)
Anti-cholinergics	35 (1%)	350 (7%)
Other	276 (10%)	574 (12%)
Not Recognised/Missing	237 (9%)	-

Peter, from Cardiff, says

"It was only through talking to other service users that I found out what medicines were available, their relative pros and cons and my rights in relation to them."

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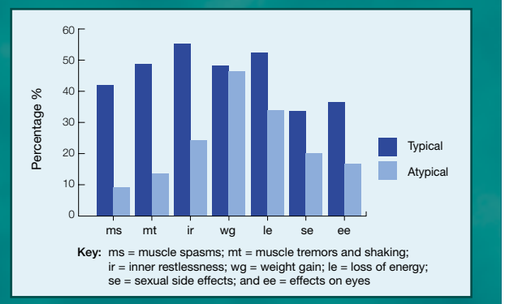
Typical v Atypical

Steve from Belfast, says

I was not told about the side effects of my medication and used to walk miles everyday due to the intensity of the inner restlessness that I felt.

Chart Three: People's experience of side-effects by current main medicine.



Key: ms = muscle spasms; mt = muscle tremors and shaking; ir = inner restlessness; wg = weight gain; le = loss of energy; se = sexual side effects; and ee = effects on eyes

Typical medicines have been available since the 1950s. They are cheap and come in a range of forms, including tablet and long-lasting depot injections. Atypical medicines have been available since the 1970s, although only came into anything like common usage in the 1990s. Take-up of the newer atypical antipsychotics has been slow, probably due to their higher costs.[2,3] Today, they come in a range of forms including tablet, syrup, quick-dissolving "velo-tabs" and, in the coming months, in long-lasting depot injections. A dose-by-dose comparison shows that atypical drugs are up to 30 times as expensive as typicals. However, when wider costs such as re-hospitalisation rates are taken into account, cost differences are sharply reduced.

Side Effects

The efficacy of all antipsychotics on the "positive" symptoms of psychoses, such as hallucinations and delusions is very similar, (clozapine, an atypical, is an exception, being effective for some people who have not responded to other medicines). It is, therefore, the side-effect profile of the medicines which distinguishes them. The range and frequency of side-effects remain constant across groups but the individual experience and intensity varies. People have different views about which medicine and which side-effect profile is "right" for them. When the side-effects become intolerable the majority stop taking the medicine.

Chart Three shows the range of side effects commonly associated with antipsychotics broken down into typical and atypical medicines. The chart does not measure the intensity of the side effects, nor does it measure how debilitating they may be to each individual. However, there is no debate that the impact of side effects on a person's ability to recover a meaningful quality of life is a real issue when deciding the appropriate medicine. As we report later, there is also a question over whether the impact of side effects impedes two-way communication and co-operation between the health professional and the person with mental illness.

Chart Three shows graphically that for all the commonly reported side effects - from muscle spasms through weight gain to effects on eyes - the side effects from atypical medicines affect fewer people. Put another way, people receiving the older, cheaper typicals are more likely to experience side effects, in the case of muscle spasms and muscle tremors up to four times as likely. Later, we look at the medicines that people found "best" and "worst" in the context of their willingness to continue taking them.

People involved in our focus groups supporting this research repeatedly complained that they were not being provided with information nor were they being involved in decision making about the medicines they were expected to take. These experiences are supported by the survey results. But was there a marked difference in the experiences of people in receipt of "typicals" and "atypicals"? The data in the question blocks refers to everyone in the sample (525). This information is then divided by the two medicine groups in the text.

We asked:

Did your doctor (psychiatrist) talk to you about your medicine?	
Yes 361 (70%)	*No 157 (30%)*

As Chart Four shows, there was a significant difference between the groups. Those people receiving atypical medicines were much more likely (79%) to be involved in discussions with professionals about their treatment than those receiving typicals (63%). These findings are in line with other research and may point to a lack of confidence on the part of health professionals in discussing the particularly serious side-effects that are associated with typical medicines.

and we asked:

Did your doctor (psychiatrist) ever offer you a choice of medicine?	
Yes 210(40%)	*No 309(60%)*

As Chart Five shows, there was again a significant difference between the experiences of people receiving atypical medicines and those receiving typical medicines. Although only a minority in both groups said that they had been offered a choice, those receiving atypical medicines were the most likely to be fully involved with 48 per cent offered a choice compared to just 35 per cent of people receiving typicals.

We asked:

Did you receive any written information about the possible side effects of the medicine you were prescribed?	
Yes 261(50%)	*No 260(50%)*

The headline figures show that only half the people diagnosed with schizophrenia and in receipt of either a typical or an atypical medicine are being offered written information on side effects. However, there is a dramatic difference when the headline figures are broken down into those receiving atypicals and typicals. Two thirds of people receiving atypicals (68%) were given written information about possible side effects, compared with just 37 per cent of those on typical medicines. Written information that can be taken away and discussed with friends and family is vital when deciding what medicine will best suit an individual. This finding supports our earlier suggestion that many health professionals may be loathe to discuss the particularly serious side effects that are associated with typical medicines.

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Information & Involvement

Chart Four: Did your doctor talk to you about your medicine?

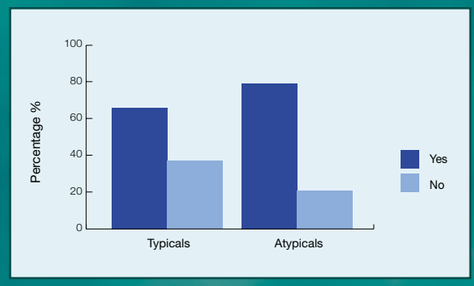


Chart Five: Did your doctor ever offer you a choice of medicine?

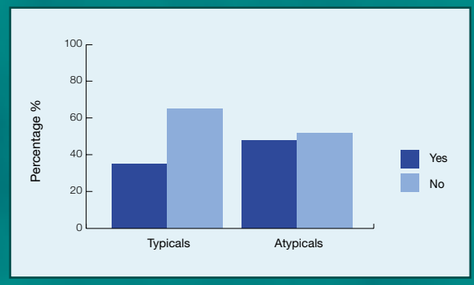
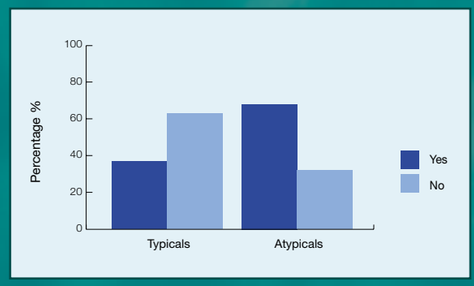


Chart Six: Did you receive any written information about the side-effects of the medicine?



Confidence in Medicines

Pat from Birmingham said,

I suffered in silence until I could take no more. In the end I became non-compliant and ended up in hospital.

Table One: Which medicine for your mental health problem was the best you have ever had?

People in receipt of either type of antipsychotic (n=1084)	Only those in receipt of typical antipsychotics (n=614)	Only those in receipt of atypical antipsychotics (n=470)
Olanzapine n=78 (15%)	Depixol n=39 (13%)	Olanzapine n=67 (30%)
Clozapine n=60 (11%)	Sulpiride n=36 (12%)	Clozapine n=57 (26%)
Risperidone n=44 (8%)	Stelazine n=23 (8%)	Risperidone n=46 (21%)

Table Two: Which medicine for your mental health problem was the worst you have ever had?

People in receipt of either type of antipsychotic (n=1084)	Only those in receipt of typical antipsychotics (n=614)	Only those in receipt of atypical antipsychotics (n=470)
Chlorpromazine n=81 (16%)	Chlorpromazine n=46 (15%)	Chlorpromazine n=35 (16%)
Haloperidol n=44 (8%)	Haloperidol n=23 (8%)	Haloperidol n=21 (9%)
Stelazine n=35 (7%)	Stelazine n=20 (7%)	Depixol n=15 (7%)

It is not uncommon for people in receipt of any kind of medicine, whether antibiotics or antipsychotics, to stop taking it at some point without or against a doctor's advice. The cost to services in Britain of people with a mental illness stopping treatment in this way is estimated to be £100 million.[6] Drug trials involving people with mental illness have high "drop out" or non-compliance rates, casting doubt over the value of statistical information derived from them. The cost to individuals cannot be quantified in financial terms. There is a risk of relapse, admission to hospital, loss of confidence in the ability to recover a meaningful life, a breakdown in trust with health professionals and so on.

We asked:

Have you ever stopped taking your medicine without the knowledge or support of your doctor?	
Yes 191(42%)	*No 262(58%)*

Again, there was a significant difference between those taking older typical medicines and those people taking the newer atypical medicines. Almost half (47%) of people receiving typical medicines had stopped taking the medicine - "become non-compliant" in the medical jargon. Just over one-third of people taking the atypicals (35%) had done the same. The main reason given by people for stopping their medicine was side-effects.

These findings would support the assumption that the sometimes severe and disabling side effects associated with the older typical medicines led to people simply stopping taking them. Further support for such an assumption would be provided by asking people to draw a Top Three of medicine "hits" and medicine "misses."

We asked 1,084 respondents who indicated that an antipsychotic was currently their first form of medicine:

'Which medicine for your mental health problem was the best you have ever had?'

'Which medicine for your mental health problem was the worst you have ever had?'

The results are set out in Tables One and Two.

A very clear pattern emerges from the two Tables shown opposite. The typical antipsychotics fill the top three worst drugs for people from both groups. The choice of "best" medicine is no doubt limited to the medicines people have gained access to. Therefore, those taking the older drugs named some of the brand leaders as best, while those people taking the atypicals named brand leaders from that category as best. However, given the limited access to and rationing of the new atypicals, it is likely that those with access to them will have experienced the older medicines at some time. The same cannot be said of people on the older medicines.

Not everyone responds in the same way to medicines. There are individuals currently in receipt of typical antipsychotics who respond well to them just as there are individuals in receipt of atypical antipsychotics who react badly to them. Best practice must build on a policy of finding, through meaningful two-way communication, the most appropriate medicine for an individual's current circumstances. However, there must be a "default" setting for those people who become ill for the first time and for those people whose ability to make decisions on their own behalf is temporarily undermined by the course of their illness.

The evidence outlined here - evidence provided by the people who use these medicines - is that atypicals are, for most people, better tolerated, associated with fewer and less severe side effects and allow for better communication with health professionals. There is strong evidence from this survey that people in receipt of atypicals are more likely to experience a meaningful relationship with health professionals and better outcomes.

New medicines are more expensive than old medicines. But the cost of a relapse - with inpatient stays, additional hours of medical staff and daycare - far outweighs the difference. Taking new medicine that you are happy with is cheaper than not taking older medicine and becoming ill.

For these reasons, atypicals should become the standard default first-line pharmaceutical treatment for schizophrenia, delivered as part of a holistic package of health and social care support.

Conclusion - A question of informed choice

Martin from Norwich said,

Initially I was put on the cheap rubbish, my weight ballooned and I felt even worse on the medication.